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Original Article

Feeding infants with Down's Syndrome: A qualitative study of mothers' experiences

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ABSTRACT

Objective: Breastfeeding may have general and specific advantages for both mothers and infants with Down Syndrome (IDS). The experiences and needs of mothers of IDS have not previously been explored, hence the aim of this study.

Design: Qualitative, with data collection via focus groups. Interpretative phenomenological analysis was used to elicit the meanings participants attributed to their experiences.

Participants: Eight mothers of IDS participated in two focus groups.

Setting: United Kingdom (UK).

Findings: Five key themes emerged from the data

1) Importance of feeding choices and methods for IDS.

2) Guilt regarding feeding IDS.

3) Health professionals were “Out of their depth”.

4) Lack of recognition of difference of IDS and typical infants.

5) Power and control of health professionals.

Key conclusions and implications for practice: Best practice from existing literature and this study is suggested, alongside the need for future research.

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Introduction

Although Down Syndrome (DS) is the most common chromosomal condition in infants (Sherman et al., 2007), only 775 families in the United Kingdom (UK) give birth to a child who has DS each year, 0.001% of the total number of births (Morris and Springett, 2014). Supporting mothers around feeding infants with Down Syndrome (IDS) is a rare occurrence for health professionals, and therefore the main expertise in these uncommon circumstances is mainly held by parents with experiential knowledge (Gribble, 2001).

Individuals with DS share common features, including phenotypical appearance, learning disability and hypotonia (Silverman, 2007; Bull, 2011) and the condition most often results from trisomy 21 (Asim et al., 2015). IDS also have a higher risk than typical

infants of cardiac and gastrointestinal defects, and cleft palate (Dennis et al., 2010; Källén et al., 1996).

The relevant literature on feeding IDS was searched in January 2015 and again in August 2015 using the electronic databases Pubmed, CINAHL, MIDIRS, Cochrane Library, NICE and Google Scholar. Key words and combinations of key words searched included Down Syndrome, Down's Syndrome, Trisomy 21, Breastfeeding, Infant Feeding and Bottle Feeding. This search highlighted the paucity of literature on the subject as summarised below.

Why breastfeeding matters

Infant feeding has short and long-term health impacts for both mothers and babies (Ip et al., 2007). Most research into parents' experiences of infant feeding have been conducted in populations with healthy term babies, or preterm and low birth weight babies (King and Jones, 2005; Lang, 2002).

Regarding IDS, Al-Sarheed (2005 p 85) stated that “The protective effects of breastfeeding against illness and complications are so significant as to interpret breast feeding as medicine for such infants”.

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Breastfeeding may have general and specific advantages for mothers of, and IDS (Flores-Lujano et al., 2009; Oliveira et al., 2010; Thomas et al., 2007) yet their experiences and needs have not previously been explored.

Gore et al. (2015) highlight the low breastfeeding rates in infants with intellectual disability, and the adverse impact this may have on health outcomes. Sooben's 2015 paper further discusses the inequalities in health experienced by those with learning disabilities and calls for more research to underpin and improve support for mothers of IDS.

Only three studies specifically addressing health outcomes associated with infant feeding in IDS were identified. Flores-Lujano et al. (2009) highlighted an increased risk of Acute Myeloid Leukaemia in childhood for IDS who are not breastfed. Bloemers et al. (2007) similarly identified an increased risk of respiratory syncytial virus (RSV) in IDS if not breastfed, especially in the presence of risk factors such as socioeconomic deprivation, passive smoking and overcrowding. Finally, Oliveira et al. (2010) found that breastfeeding for less than 6 months was positively associated with malocclusion in IDS.

Only one paper by Lewis and Kritzinger (2004) specifically aimed to explore parents' experiences with regards to feeding IDS. This describes symptoms such as hypotonia linked with slow sucking, poor lip seal, uncoordinated suck/swallow/breathe, aspiration, reflux, coughing and vomiting. However, no discussion is given regarding how these infants were fed.

Around half of live born IDS have congenital cardiac disease (Irvine and Chaudhari, 2012) and many will require surgical correction. Marino et al. (1995) found reduced cardiorespiratory stress in breastfed infants, compared to those taking feeds by bottle. Edwards and Spatz (2010) discuss the importance of breast milk feeding for babies requiring neonatal surgery and for babies requiring frequent, prolonged hospitalisation.

Prevalence of breastfeeding

In the UK, rates of breastfeeding initiation for IDS are lower than for healthy babies (Aumonier and Cunningham, 1983; Martin, 1978). This is not surprising given that only three publications were identified which aimed to offer evidence-based guidance around feeding IDS. Ivan and Cromwell's (2014, p107) guidance for primary care management of IDS states:

"If the ability to suck or latch on is impaired, consider formula supplementation until a successful breastfeeding pattern is established"

However, this statement is not evidenced and ignores the option of giving expressed breast milk, which the World Health Organisation (2003) recommends as the next best option for infant feeding and maintaining maternal milk supply.

The clearest clinical guideline is provided by Thomas et al. (2007) in the Association of Breastfeeding Medicine protocols for feeding the hypotonic infant. This paper states that feeding in IDS has not been specifically studied and suggests future research needs around feeding hypotonic infants.

Current literature identified numerical data rather than the lived experiences of participants; the voice of the women is missing. Qualitative descriptions of parents' experiences are absent from the academic literature, though internet forums, blogs and mother to mother support groups have a number of rich, detailed, personal accounts of feeding an IDS (Dempsey, 2013; Abianac, 2014).

The aim of this study was to explore the experiences of mothers of IDS regarding feeding, and to provide information to better

inform health professionals caring for new mothers and their babies.

Methodology

This study comprised part of the corresponding author's dissertation for the Master of Public Health degree. Hence the fieldwork and initial analysis was completed by the corresponding author, with later validation by the second author.

Mothers of children with Down Syndrome were approached and recruited in 2015 by the corresponding author through parent support groups via Facebook and email. Participants were a self-selected convenience sample and the demographic characteristics and shown in Table 1. All participants who elected to take part in the research participated in the focus groups. Two focus groups were carried out with a sample of eight mothers of IDS. Inclusion criteria were a child under the age of five years, born in the UK, and mothers who were fluent and literate in English. No one who volunteered for the study was excluded.

Ethical approval

Ethical approval was obtained from Staffordshire University Research Ethics Committee. Written, informed consent was obtained from participants prior to data collection. Data was stored in a locked filing cabinet in a locked office. Audio files and transcripts and analysis were saved to a secure, password protected server.

Data collection

Two, 1-h long focus groups were held, one in the West Midlands and one in the North West of England. Groups were held at a time and location suitable to the participants and a free crèche was provided for children. The corresponding author and an assistant ran the focus groups, supported participants and collected field notes. Focus groups were audio recorded and transcribed in full by the first author.

Data analysis

Field notes, initial instinctive thematic analysis and researcher reflection were reviewed immediately after each focus group by the corresponding author. All participants in the focus group were given a pseudonym and any identifying features were removed prior to analysis.

Interpretative phenomenological analysis (IPA) was used to explore how mothers perceived and explained specific experiences (Smith et al., 1999). Themes were compared and contrasted across full transcripts and field notes by the first author and a list of identified themes was produced. The second author independently read the transcripts and field notes and identified key themes. These were discussed until agreement was reached. Internal validity was also verified through cross checking the derived themes against the participants' verbatim accounts. Participants were also given the opportunity to comment on the themes identified, a method of data validation through member checking (Birt et al., 2016) with all concurring that the themes reflected their experiences.

Findings and discussion

This is the first qualitative study to our knowledge to explore the experiences and decision making of mothers feeding IDS, using interpretative phenomenological analysis. Pseudonyms are used to ensure anonymity.

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